

# Making Lainie's Angels a Part of Your World

## *A Note to Our Prospective Grant Recipients*

Right now, thousands of families across the United States are facing one of the most dreadful experiences possible – caring for a child who is suffering from cancer or a blood disorder. And even with knowledgeable and compassionate doctors, nurses, and social workers by their side, most families will navigate this path feeling isolated and alone.

That's where we come in.

**Lainie's Angels is dedicated to bringing parents who have experienced childhood cancer and blood disorders into contact with families whose children have recently been diagnosed.**

This case statement is a nuts-and-bolts guideline to incorporating the Lainie's Angels program into your organization. Here you'll learn about who we are, how we work, and how a well-developed program of peer support can make the lives of your patients and their families just a little bit better. Most importantly, though, you'll learn how you can play a role – because in the end, we're relying on you to help our mission take flight.

## *Turning A Tragedy Into Hope*

In June 2000, 12 year-old Lainie Afendoulis, the eldest daughter of Stathi and Emily Afendoulis, succumbed to Ewing's Sarcoma. Lainie's battle had lasted over two years. During that period, Stathi and Emily faced a gamut of complex emotions and concerns, not least of which was a pervasive sense of having nowhere to turn for support and advice. Indeed, there were many kind and capable people to assist Lainie – doctors, nurses, social workers, psychiatrists – but no group in place to help *them*.

Lainie's passing, however, bore a vision of hope and compassion. Through their tragedy, Stathi and Emily were inspired to create a network of parents who had been down the same road, and who would be willing to offer others comfort, direction, sympathy and peer support.

### *Our Mission*

*Lainie's Angels will meet an important, widespread, and currently unmet human need – the need families of children with cancer and blood disorders have for ongoing support. Lainie's Angels will provide this support by creating and sustaining Family Support Groups with institutions that treat these children. Lainie's Angels will also speak out publicly on these families' behalf to make sure their neighbors across the nation understand their need.*

## Lainie's Angels – A Program Overview

The Lainie's Angels program is based on the success of a model for patient support and advocacy developed by CURE Childhood Cancer Association for the Golisano Children's Hospital at Strong, University of Rochester Medical Center. The history and effectiveness of this program has been documented in an article published by the Journal of Psychosocial Oncology Vol. (2), 1992. The 20-plus year success of the CURE program has provided the medical and social services community with a viable working model toward providing parent peer support. Lainie's Angels vision is to expand this model around the country, assisting as many families as possible, in as many institutions as possible.

The benefits of a strong, experienced peer advocate cannot be overstated. The Rochester study concluded that parents can learn adaptive behavior and essential coping strategies from "veterans." It also found that parents can better respond to a doctor's recommendations if they have been in consultation with parents who have faced the same difficult decisions.

**The beauty of the Lainie's Angels model is that each sponsoring organization plays a vital role in the implementation of its own program. We will offer training, guidelines, sample working models, suggestions and ongoing support. As a grant recipient and program sponsor, though, you will decide how to make the program work best for your hospital or clinic.**

### A Real Life "Angel"

The key figure in the Lainie's Angels program is the Parent Advocate, or "angel." This is a mother or father whose own child had at one point been diagnosed with some form of blood disorder or pediatric cancer.

Following a comprehensive training program (detailed below), this parent becomes a qualified peer-support advocate, capable of providing families something few others can: guidance, empathy, and support based on the very experience of "having been there."

**The Parent Advocate is meant as a compliment to a patient's existing medical/psychosocial network. They do not to take away from any professional's pre-existing role. They do not claim to be a social worker, nurse or psychiatrist. They are not at liberty to overrule or impede a doctor's advice and guidance. Rather, they will assist families in understanding diagnoses on practical terms and what may or may not lie ahead as a result of medical treatments.**

*"...Because onset of childhood cancer is sudden, unexpected and often life threatening, the experience can often leave all family members with an extreme sense of hopelessness, helplessness, and isolation. The importance of a person's support network during times of crisis has been well documented.... Because cancer in children is relatively rare, support systems for information and sources of guidance are limited... Several studies, however, have underscored the importance of uniting patients and families with other individuals who have been through or are going through a similar experience for mutual guidance and support... By learning adaptive behavior and coping strategies from 'veterans,' patients and parents receive more personal advice and understandable information than professionals can give. They also can experience empathy from individuals who can personally identify with them."*

**- Excerpted from the Journal of Psychological Oncology, Vol. (2), 1992**

# “A Boot Camp For Angels”

## Training to Become a Parent Advocate

Thorough, expert training is the key to the smooth transition of the Parent Advocate into the hospital/patient environment.

The Lainie’s Angels training staff consists of experienced, knowledgeable professionals who specialize in pediatric cancers and blood disorders. Our training team is comprised of doctors, social workers, two current Parent Advocates, the executive director of the CURE Program, and Stathi Afendoulis, chairman and founder of Lainie’s Angels.

Once selected, the Parent Advocate is sent to The University of Rochester Medical Center (Rochester, NY) for an extensive two-day training session. Combining both one-on-one and clinical instruction, the course prepares the individual to become a fully functioning member of the pediatric oncology/psychosocial team, capable of assisting both parents and patients. Training culminates in actual clinical rounds at the university hospital.

**Phase one** of the training program provides the skills necessary for the Parent Advocate to identify the members of the health care team, define his or her role, and set up a network, or Parent Advocacy Group, which includes the parent and patient, medical and nursing staff, psychosocial staff and community outreach group.

**Phase two** focuses on the implementation of the Parent Advocate function. Advocates will receive specific training with respect to the various members of the health care team:

1. **Patients and Parents** – Advocates will learn how to make initial introductions, conduct follow-up visits, and hold one-on-one meetings. Moreover, each advocate is responsible for creating an on-going “coffee-hour.” This is a weekly meeting at which parents can meet and socialize. Participants in these meetings may choose to have informal discussions of issues related to each patient’s specific situation, and the effects that treatments are having on the family.
2. **Medical and Nursing Staff** – The Parent Advocate will receive sufficient training to make a thorough presentation explaining their role to members of the pediatric and nursing staff. This meeting is crucial for both the advocate and medical staff, as it allows the advocate an opportunity to show how their role compliments the care already being given by the doctors and nurses.
3. **Psychosocial Staff** – The Parent Advocate will receive training in social work/counseling, child-life support and tutoring, patient and crisis management, and patient assessment and strategy. This will help them compliment the work of social workers, child psychiatrists, and child-life specialists.
4. **Community Outreach Groups** – The Parent Advocate will be briefed as to what resources, such as national organizations (e.g., National Cancer Society) and local support groups are available to them in order to help create a volunteer organization that can assist them. The development of these relationships is one of the primary responsibilities of the Parent Advocate.

## The Parent Advocate in Action

Upon completion of the course, the Parent Advocate receives a training manual and support materials to help them structure their own program. Periodically, our Parent Advocates return to Rochester to share feedback, gather new insights, and sharpen their skills. We strive to make training an ongoing process, so as to ensure that the advocate remains as prepared and knowledgeable as possible.

Even after their formal training concludes, the Parent Advocate receives a continuum of support from the Lainie's Angels organization. We urge steady communication between our staff and our Parent Advocates, and we provide ongoing help through our Web site ([lainiesangels.org](http://lainiesangels.org)), and by phone.

**The role of the Parent Advocate is a fluid one. Even though they will fulfill certain core responsibilities essential to the success of the program, the Parent Advocate's services can be tailored by you to meet the specific requirements of your hospital or clinic.**

### General responsibilities:

1. Meet each family soon after diagnosis and act as a liaison between family and staff.
2. Assist the patient and family when the child has been diagnosed with a chronic or life-threatening condition.
3. Inform the appropriate staff member of issues pertaining to the needs of the patient and family.

### Specific Responsibilities:

1. Provide emotional advocacy and support to the patients and families that are treated by the Division of Pediatric Hematology-Oncology.
2. Visit each family during any hospital stay and provide planning and preparation for hospital procedures, offering emotional support and information regarding hospital resources and programs.
3. Come equipped to participate in or attend:
  - Parent coffee hour meetings
  - Psychosocial team rounds
  - Hospice and bereavement calls and visits
  - Funerals and wakes
  - Hematology/Oncology problem rounds with psychosocial staff
  - Daily record maintenance on families and services
  - Psychosocial training seminars

**Once settled into the hospital/patient environment, the Parent Advocate is encouraged to build a team of volunteers. This not only helps to alleviate burnout, but it also provides a tremendous resource for the hospital itself, in the form of a network of volunteers that can assist in a multitude of ways.**

## What We Ask Of You

Trust is the key element to the success of the Lainie's Angels program. It is imperative that parents, doctors, and the patient's entire circle feel comfortable with their new team member.

Although Lainie's Angels is involved in the selection process, our program sponsors have the ultimate responsibility of choosing their Parent Advocates. We realize that what works for one clinic or hospital may not work for another – so each sponsor is free to recruit whomever they feel will “make the best fit.”

That said, the best candidates are often those whom you or your staff already know. These individuals understand the specifics of the sponsoring institution, can quickly establish rapport with other team members, and move smoothly into their role in the hospital/clinic environment.

Who do you know at your hospital, clinic, or local community that would make the perfect “angel?” Who immediately comes to mind as empathetic, motivated, and concerned, and can serve as a strong model for coping?

**In the end, you know what works best for your own institution. Perhaps you'll need more than one Parent Advocate to handle the job; whatever the case, we'll be right there to consult with you, and to make the selection process go as smoothly as possible.**

### **Obtaining A Grant And On-going Funding**

Without proper funding, no program, no matter how good its intent, can hope to thrive. That's why we are prepared to provide substantial initial funding to any qualified hospital or clinic that shows a motivated desire to support an on-going commitment to a Lainie's Angels program. Initial grant awards will vary in size from \$25,000 to \$50,000, based on the size and scope of services offered by the institution. (Please note that sponsoring institution will be responsible for providing a basic office environment, which may include a telephone, desk, beeper, computer, etc.).

**This initial grant is designed to fully fund the Lainie's Angels program for a period of three years. During this time, as the program takes root and expands, and as the network of volunteers under the Parent Advocate grows, we ask that the sponsoring institution work towards establishing a self-funded program. To this end, Lainie's Angels and the individual Parent Advocate will play a key role, both in advising the institution and in promoting efforts towards creating a framework for local community fundraising efforts.**

*“It is wonderful to have a Parent Advocate program as part of the Pediatric Oncology Division at Golisano Children's Hospital at Strong. They provide an invaluable service to our patients. I cannot imagine how we managed without them before the program was established.*”

**Barbara L. Asselin, M.D.,**

Associate Professor of Pediatrics and Oncology, University of Rochester Medical Center, Medical Center, Golisano Children's Hospital at Strong

## **What's Next**

We hope this case statement has addressed the basic issues of how to employ our program in your institution. But what we've laid out here merely scratches the surface. We urge you to contact us. Speak with Stathi Afendoulis and other key members of the Lainie's Angels organization, including parents who've benefited from the program. Above all, we want our sponsors to be informed – the more they know about us, the more they'll appreciate our mission.

Thanks to individuals such as you, the vision of Lainie's Angels is becoming a reality all across the nation. We are able to assist healthcare professionals, parents, patients and those that love them navigate difficult waters, and come to terms with what is probably the most difficult period they've ever experienced.

We may not have all the answers -- no one does. But at the very least, we can do as much as we can to comfort and assist parents in a way that few others can; we can say, "I know how you feel, I've been there."

**Lainie's Angels**  
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